



Family News

July 2003

News and Information for Families of individuals at Muscatatuck SDC and Madison State Hospital during the transition to community-based services.

Indiana Protection and Advocacy Services

Indiana Protection and Advocacy Services (IPAS) is a federally funded state agency, independent from other state agencies and service providers. IPAS works to protect and promote the rights of individuals with disabilities and/or mental illness through empowerment and advocacy.

IPAS was established in 1977 in response to federal requirements for a program to advocate for the rights of individuals with developmental disabilities. This was a result of requirements that came from the Developmental Disabilities and Bill of Rights Act, known as the DD Act, administered by the Administration on Developmental Disabilities (ADD). Since then, five more programs have been added. The staff and programs of the Administration on Developmental Disabilities are part of the Administration for Children and Families of the U.S. Department of Health and Human Services.

Each of the IPAS programs serves the advocacy needs of a specific group of individuals with disabilities. Over the past 25 years, IPAS staff has worked very hard and effectively to empower thousands of Hoosiers with disabilities and their families as they strive to live their lives as independently and productively as possible. Through providing information and referral, individual and systemic advocacy or legal

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FSSA Secretary Hamilton Responds To Your Questions

(Continued from June 2003 Q & A on the Central State Hospital (CSH) Closure Evaluation Project.)

Q What is the well being and quality-of-life of consumer residents transitioned from a state-operated facility (SOF) into home and community-based care? And, how is their well being and quality-of-life measured?

A According to Dr. Eric R. Wright, Associate Professor of Sociology at IUPUI and Project Director for the Central State Hospital (CSH) Closure Evaluation Project, the survey data gathered from former CSH consumers indicates that they feel much better about their lives after leaving CSH. This is based on annual surveys conducted during the first five years following their discharge from CSH. Using standardized instruments designed to assess quality-of-life, psychological well being, and satisfaction with services, the research team led by Dr. Wright, finds that — regardless of whether a client was discharged to a community facility or to another SOF — the consumers felt they were much better off than they were at CSH. Indirect measures reflect other positive changes in these consumers' lives. They report having larger support networks in the community. And, the number of individuals who are employed has also increased since leaving CSH. In 2004, the research team plans to re-interview these individuals and

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ask the same battery of questions. This will enable researchers to evaluate the long-term impact of deinstitutionalization and the extent that consumer hopes for reintegration into the community have been achieved.

Q How do the deaths of those released from a state-operated facility into home and community-based care compare to the deaths of the general population?

A As of March 2003, 70 (18.0%) of the former CSH patients had died, and public concern about the high mortality rate remains strong. While the mortality rate is, in fact, higher than the Indiana unadjusted all-cause mortality rate, the research team's analysis of causes of death suggest that most of the deaths were the result of physical ailments, many of which were evident at the time of discharge from CSH. Further, Dr. Wright's analysis of the death records indicates that there have been fewer deaths that can be attributed to service-related problems over the past 8 years than occurred in the one year period prior to the decision to close CSH. It is also difficult to compare the CSH cohort's mortality rate with that of other SOFs because of the dramatic changes in the typical length of stay in SOFs since 1994. Ultimately, while the mortality rate should be a cause for public concern, there is little scientific evidence to suggest that continued institutionalization of these individuals would have delayed their deaths.

The evaluation concludes that it is important to keep in mind that - in the past - mental illness consumers were often placed in SOFs specifically to make sure that they received care for serious chronic physical health problems. Hence, the higher mortality rate may be an outcome of a higher prevalence of significant health problems as

well as problems in accessing primary health care services. Historically, consumers of mental health services, like many underinsured and disadvantaged Americans, have had limited access to primary health care services, a situation that - according to Dr. Wright - is likely to intensify in the coming years with recent challenges in state and federal funding for Medicaid and Medicare.



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representation, the IPAS staff seeks ways to empower clients through assisting or providing them with effective approaches to problem resolution.

IPAS carries out the functions of six federally funded programs for Indiana. Each program advocates for the rights of the individual with the disability. To receive services, each program requires that the problem must be related to the person's disability, such as a denial of a right or discrimination.

- **CAP**- Client Assistance Program
- **PADD** – Protection and Advocacy of the Rights of Individuals with Developmental Disabilities
- **PAIMI** – Protection and Advocacy for Individuals with Mental Illness
- **PAIR** – Protection and Advocacy for Individual Rights
- **PAAT** – Protection and Advocacy for Assistive Technology
- **PABSS** – Protection and Advocacy for Beneficiaries of Social Security

IPAS contact information is as follows
1-317-722-5555, 1-800-622-4845
www.IN.gov/ipas



Key Priorities

To be achieved by June 30, 2005

FSSA Works for Hoosiers

At FSSA, our mission is clear: to help Indiana's children, families, adults and seniors be safe and healthy--and as independent and self-sufficient as possible.

Expand home and community-based services for an additional:

- 1,000 senior citizens
- 1,000 people with developmental disabilities
- 800 troubled children
- 480 people with mental illness

Prevent problems and build self-sufficiency

- Healthy Families: screen 90% of births; offer services to 100% of at-risk families; ensure that 99% participants have no substantiated abuse or neglect
- First Steps: serve 18,000 children, with 95% achieving documented developmental gain
- Public Assistance: Increase earnings and savings of families by 15 percent
- Supported employment: Meet or exceed the national average for people with disabilities or severe mental illness
- Long term care insurance: Help 15,000 Hoosiers acquire new policies

Keep Hoosiers healthy and safe

- Hoosier Healthwise: More than half of children will receive at least five well child visits from birth to 15 months
- Chronic disease management: Medicaid clients who have asthma, congestive heart failure, diabetes and HIV/AIDS will achieve specific clinically measurable improvements each year
- Hoosier Rx: Double enrollment to 30,000

Accountability

- Publish, implement and operate with consistent metrics throughout FSSA to assess and improve quality and effectiveness of services
- Earn a top five national rating for efficient use of information technology in a social services agency





Keep In Mind

Indiana Protection & Advocacy Services
317-722-5555 or
1-800-622-4845

Div. of Disability, Aging & Rehab
Services:
800-545-7763

Div. of Mental Health & Addiction:
800-901-1133

MSDC/MSH Info Hot Line:
800-903-9822

Ombudsman: **800-622-4484**

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Future Issues

- ◆ Resources
- ◆ Your Ideas

Each child is an adventure into a
better life—an opportunity to change
the old pattern and make it new.
Hubert H. Humphrey

The Web site for FSSA is
receiving a much needed ‘face-
lift.’ You may not recognize it
at first glance.
This newsletter, along with
previous editions, may be
viewed at:
www.in.gov/fssa/transition

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